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Activities of Daily Dying: Perspectives from Occupational Therapists in Hospice Care

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Activities of daily dying: Perspectives from occupational therapists in hospice care

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Abstract

Occupational therapy (OT) is a form of rehabilitation that focuses on participation in everyday life tasks. Hospice care is an approach to care that focuses on promoting quality of life at the end of life. There are currently very few occupational therapists (OTs) that practice in this field. This study explores the experience of OTs who work in hospice care. Methods: Four participants were interviewed two times each using a narrative based, semi structured interview technique. Data was analyzed using narrative methodology and thematic analysis. Seven major themes emerged from the data: *Hospice OT Mindset, Collaboration, Little Bit of Rehab, Little Things Big Impact, Participation is Pain Management, Role Release, and Partnership.* Discussion: These themes point to the distinct value that OTs can bring to practice in hospice care. The findings of this study along with the review of the current literature demonstrate that it is in occupational therapists' scope of practice to work in this non-rehabilitative field. OTs that work in hospice can give patients the ability to participate in meaningful occupation as they move through end of life care.

Acknowledgements

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I would like to thank my dad for always demonstrating motivation and hard work. Finally, I would like to thank my mom for teaching me to handle life and hardship gracefully.

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Chapter 1: Introduction

Background

Hospice care has a long history around the world and was first introduced in the United States in 1963 (History of Hospice Care, 2016). Hospice is an approach to care that can be offered in many different settings like a home, hospital, or long-term care facility. It is appropriate when a person has six months or less before passing away. The goal of hospice care is a peaceful and comfortable death for the patient, along with support for the family throughout the whole process, even post death. Picard and Magno state (1982), "Hospice care is about adding life to the patient's remaining days, not adding days to the patient's remaining life" (p. 597). Therefore, the focus of hospice is on caring instead of curing, this means that the focus is on pain relief, comfort and enhanced quality of life. Hospice care is in high demand; 1.4 million Americans utilized this service in 2017 and this is projected to increase in the years to come (Bryant, 2019). One study shows the demand for hospice care has been growing as patient numbers have tripled in the last two decades (Bryant, 2019). With hospice becoming an ever-growing asset to healthcare, it is important to know how OT's role can be utilized in this field.

There are similarities in philosophies between hospice care and OT. The original American Occupational Therapy Association (AOTA) position paper on OT and Hospice (1986) states that

> OT and hospice care share the goal of helping people with life-threatening diseases adapt to changing life situations in order to live as fully and comfortably as possible. Both acknowledge the importance of the physical and social environments and seek to promote caring communities (p. 1).

AOTA describes OT as, "the only profession that helps people across the lifespan to do the things they want and need to do through the therapeutic use of daily activities" (AOTA, 2018).

This lifespan focus indicates that end of life and palliative care is in OTs realm. AOTA defines palliative care as, "an interdisciplinary team approach used for people with serious or life-threatening illnesses to enhance their quality of life" (Allen, 2015). The team's goals include pain management, comfort, offering support systems to the patient and their family, and blending psychosocial and spiritual needs into the care received during their end of life (Chase, 2010). In short, they help with the process of dying because OTs focus on participating in meaningful occupations while considering both psychosocial and physical needs of the patient. Given OT's unique qualities and the similarities it shares with palliatives care, the two professions can make a complementary team. Unfortunately, it is rare for OTs to be part of the palliative care team. Several barriers to the inclusion of OT in hospice care have been identified in the literature and will be further discussed in the literature review below.

These barriers lead to a very small number of occupational therapists working in hospice care. A mixed method study out of Australia by Keesing and Rosenwax in 2011 reported that only 4.9% of therapists are working with dying patients and only 8% of occupational therapists are reportedly working in hospice care in Canada (Yeh et al., 2018). In the 2000 AOTA Compensation Final Report, a document that summarizes data about occupational therapy practitioners in the United States, only 1% of OTs were working in hospice care. In 2015, the last year that data is available, the report did not even mention hospice as a practice setting.

OTs role and scope of practice in hospice care have not been clearly defined (Russell & Bahle-Lampe, 2016). It was not until 1986 that AOTA endorsed a position paper on OTs role in hospice; this paper confirmed, "people can lead productive and meaningful lives despite a terminal illness and that occupational therapy provides an essential service in this process" (p. 839). A patient with a terminal illness may still wish to complete meaningful roles, which is

why it is clear OTs should have a more prevalent role in hospice care. OT's mindset may be different in this setting. An updated version of the position paper on OT and hospice paper by Trump, Zahoransky, & Siebert (2005) state that occupational therapists who "work in hospice frame their practice on comfort and quality of life rather than rehabilitation" (p. 671).

One of OT's main roles is to assist patients with completing meaningful occupations. When dying interferes with completing occupations, one's overall well-being can be affected. This can result in occupational deprivation. Occupational deprivation was defined by the Australian Journal of Occupational Therapy (OT Australia, 2016) as, "the condition of being prevented or precluded from participation and engagement in occupations of necessity, obligation, and choice" (p. 445). OTs can help by implementing interventions and modification to encourage patients to take part in meaningful activities. Interventions offered by OTs during end of life care could include activities of daily living (ADL), consisting of dressing, bathing, and functional mobility, and instrumental activities of daily living (IADLs), including meal preparation, home management, and health management, rest, sleep, and leisure participation could also be a focus. OTs address psychosocial and behavioral health, which would include engaging patients in reflections about their life, writing letters to family, collaging, and understanding the process of dying. Intervention could also include the patient's family. AOTA (2005) stated, "Continuation of importance rituals of everyday activities can support meaningful purpose in the dying person's final days" (p. 674). One of many slogans used to describe OT is "Living Life to the Fullest" and to truly encompass the full meaning of this phrase, OT must address end of life care (AOTA, 2019) .

My Inspiration

My mother passed away gracefully at age 53 in a hospice care home. Dying gracefully, at any age can be a difficult experience. My mom saw this as a challenge. She had a difficult time finding a way to leave a legacy and to prepare me for the rest of my life without her. She grappled with the inevitability of the situation, facing her own mortality and saying goodbye to loved ones. Eventually, as a coping mechanism, she found tasks to complete, like organizing and giving away jewelry to friends and arranging papers to make everything easily accessible when she was gone.

My personal experience has taught me that with the end of your life, one's whole being does not need to decline. With help to continue occupational roles and activities, one's mind and soul can continue to grow.

The last three months of my mother's life coincided with my first three months of OT school. I began to learn about the importance of meaningful occupation and what one's life would be like without them. Three years into my education, I looked back on her journey and realized a lot of her coping mechanisms involved participating in meaningful occupations. This sparked an idea about how valuable OT could be in a hospice or palliative care setting. As we carry the knowledge about positioning, transfers, and anatomy, we also have been trained to focus on meaningful occupations.

As noted in the following chapter, there is limited research that has investigated the personal accounts of OTs in hospice care. In addition, the small amount that does address these issues was completed ten or more years ago. Several references used in this research are older, however they hold pertinent information regarding hospice and OT. Therefore, although there are similarities between OT and hospice care philosophies, little is known about the everyday

experience of occupational therapists who are practicing in hospice care. The purpose of this study was to explore the experience of OTs who work in hospice care. To this end, I used qualitative methods, detailed in Chapter Three, to investigate the everyday experiences of occupational therapists working in hospice care. Denzin and Lincoln (2011), experts in qualitative research methods, suggest that one way people can learn about topics is through examining stories shared by people directly involved in the topic of interest. This study uses stories told by occupational therapists working in hospice care to describe how occupational therapists can operate in a hospice care setting.

Research Questions

As I developed the idea for this study, I gathered literature related to OT and end of life care. The combination of my personal experience and what I read in the literature lead me to develop three research questions that guided the design and implementation of this study. These questions are:

1. How do some OTs who work in hospice care spend their time?
2. What barriers exist to integrating OT and hospice services?
3. What is the experience of an OT in hospice care?

Chapter 2: Literature Review

As noted in the introduction, there is a very small amount of literature that investigates the personal accounts of OTs who work in hospice care. The majority of the literature that is available about OT and hospice care reviews possible roles for OTs in hospice settings and discusses the barriers to integrate OT and hospice services. This section summarizes the literature in these two areas and integrates literature about end of life and quality of life that did not directly mention OT, but clearly supported the need for OTs role in hospice care.

Occupational Therapy Roles in Hospice

Much of the literature related to this topic concentrates on descriptions of the possible roles OT could play in end of life care. Despite the barriers described below and the lack of OTs practicing in this area, many authors argue that OTs can have a crucial role in this setting. Trump et al. (2005) states, "The ultimate outcome of hospice is a good death, with the focus on the patient's and family's quality of life during the time that is left" (p. 673). As noted in a document detailing the role of OT in end of life care published by AOTA (2011), OT addresses factors that affect quality of life, similar to the goals of hospice. Therefore, hospice and OT share the goal of reaching a good death. These could include, maintaining function and involvement in desired life activities, gaining a sense of control, staying connected to relationships, and continuing to search for a meaning and purpose in life. An article by Russel and Bahle-Lampe (2016) stated that OT's role in end of life care could consist of "identifying life roles and activities that are meaningful to clients and addressing the barriers to performing these activities" (p. 4). Russell and Bahle-Lamp (2016) addressed these barriers by saying, "therapists can further offer education in terms of safe transfers and use of orthotic devices in order to extend hospice care in a home setting" (p. 4). Pitzin (2009) found that 98% of OTs who did not work in

hospice agreed that there were roles for the OT profession in hospice care. The three main functions the participants identified were positioning, home modification, and caregiver training. Bognot (2018), an OT who practices in hospice care, states in an article that her role is "to support what matters most to clients and their families, even as the body goes through functional declines" (p. 17). Keesing and Rosenwax (2011) interviewed caregivers in the qualitative portion of their study who reported that their loved ones were not participating in meaningful occupations, leading to occupational deprivation. Occupational deprivation is further defined as, "a state in which people are precluded from opportunities to engage in occupations of meaning due to factors outside their control" (Whiteford, 2000, p. 200). This lack of participation created a clear role for occupational therapists to step in.

The statement paper, written for AOTA by Trump et al. in 2005, briefly describes the occupational therapy process in hospice. To start, a member of the hospice team may refer the OT to evaluate a patient. During the evaluation process, the OTs main goal is to grasp the patient's needs and priorities and to "understand the client's and caregiver's expectations of dying" (p. 672) through a general interview process. The OT's next role is to create an intervention plan with the patient, family, and hospice care team. To guide the interventions, the approaches most commonly used by OTs are modification to the environment or activity demands and prevention of injury or isolation (Trump et al., 2005). The OT process of "evaluating, intervening, and reevaluating is iterative rather than linear, as the client's needs and priorities evolve" (p. 672). Hospice patients may have sudden declines in health status, therefore accepting that the process is iterative and everchanging is required as a hospice OT. This resource also included case studies that provide specific examples of the OT process in hospice

care. Trump et al., (2005) goes on to sum up the importance and role of OT in hospice by stating,

> The ability to identify a person's occupational roles and values, and to address these roles and needs through appropriate intervention to ensure a quality of life in the dying process, makes occupational therapy an important contributor to hospice care (p. 674).

A scoping review out of Alberta, Canada by Yeh, McColl, & Huang (2018) noted that the role of OT in hospice care is often misunderstood. They reviewed 74 articles to explore the unique roles OT has to offer in hospice care. A variety of possible roles emerged from the review. Sixty of the 74 papers discussed the importance of focusing on valuable occupation for the patients. They also found in 15 articles that OTs helped patients to participate in doing occupations like community outings, personal care, and leisure activities. Twenty-eight articles defined one of the roles for the OTs to be "affirming life and preparing for death" (Yeh, et al., p. 108). This was further defined as promoting autonomy, helping patients to participate in life roles, and preparing for death by assisting with closure and education on end of life issues (Yeh et al., 2018). Thirty-six of the articles discussed occupational therapists' role in teaching assistive devices, home modification, energy conservation, fall prevention, and positioning (Yeh et al., 2018). This scoping review concluded that occupational therapists' main role in hospice care was to promote the patient's experience of a "good death." A "good death" has been defined as "peace, holism, aware preparedness, a sense of control, and being able to contribute to others" (Jacques and Hasselkus, 2004). This can have many different attributes. Jacques and Hasselkus (2004) found that participating in occupations and preparing for death by sharing life stories and saying good-bye to loved ones are key components to having a good death. They go on to state that "the good death is about each person's good death, a unique experience for each dying person" (p. 52). In order to create a good death, the authors suggested looking at

occupation under a different context, "the context of dying provides a unique temporal and sociocultural experience, remaking the 'ordinary' into 'extraordinary' nonrepeatable meaningful events" (p. 52). As an OT, providing the patients with one more ordinary opportunity to complete a meaningful occupation can help lead to a good death.

Chase (2010), an OT who worked for a home health agency that works with hospice care, described her process of developing a practice in hospice care. She stated, "my role at the agency expanded to include developing recommendations and training in the use of assistive technology such as personal emergency response systems; teaching about positioning needs to increase client comfort and prevent pressure ulcers; and problem-solving for bathing skills" (Chase, 2010, p. 3). Hospice care is team-oriented approach and her experience highlighted how an OT can educate other team members about ways to enhance quality of life for their patients. She acknowledged the need for more exploration on this topic stating "I am proposing that our profession look at loss of all types, from loss of function or independence to end-of-life issues, through an occupational lens to provide a framework for deepening our understanding and exploring our role in this experience" (Chase, 2010, p. 3). Chase acknowledged the importance and uniqueness of OT's role in end-of-life care and emphasized the need for more research and advocacy to promote this area of practice.

A study completed by Daverman (2015) looked at identifying occupational roles through reminiscing and storytelling at the end of life. The Role Checklist and structured interviews were used to assess four case-study subjects and create a plan for specific interventions. Daverman used findings from this study to create a metaphor linking OT and hospice. This metaphor starts with the idea of a bridge. The beginning of the bridge is Point A and the end of the bridge is Point B. Meaningful occupation is the bridge material connecting Point A to Point

B and the OTs are the engineers building the bridge by linking meaningful occupation to accepting the end of life. Daverman reported that by focusing on occupations "individuals are able to gain a sense of control over their world and share their individual selves with the things that they love" (2015, p. 31). He identified reminiscing and storytelling to be the scaffolding of the bridge, helping the OTs to provide a base for the bridge, by identifying the meaningful aspects of life (Davermen, 2015).

A qualitative study by Davis, Asuncion, Silangcruz, and Dyke (2012) highlights another important role OT can have in the hospice care setting. Six OTs working in hospice care were interviewed to look specifically at their listening behaviors and experiences. The participants identified a crucial need for listening to the patients in this setting. Specific listening behaviors "helped facilitate meaningful conversations with their patients and allowed patient needs and values to emerge" (Davis et al., 2012, p.18). This study highlights an important skill that OTs are trained to do in their education to facilitate client centered practice. This study identifies occupational therapists' role to be "to listen, support, advocate, educate, mediate, and facilitate to improve their patients' quality of life and death in hospice and palliative care settings" (Davis et al., 2012, p. 18).

This summary shows that though there is research present on occupational therapists' role in hospice, it is limited. Picard and Magno (1982) urged OTs who were currently working in hospice care to share their work to promote OTs role through writing journal articles, giving workshops, and partnering with academic programs. They hoped this would "bring the pertinence of their work to the attention of their colleagues" (Picard & Magno, 1982, p. 598). Unfortunately, this call made more than 30 years ago has not been adequately answered.

Barriers

The common barriers of integrating OT and hospice were frequently discussed in the literature. In a study by Pitzin in 2009, the top barrier found "was lack of awareness by other disciplines of what OTs can offer palliative patients" (p. 15). Keesing and Rosenwax (2011) stated that "OTs viewed their role as misinterpreted by other health professionals, people who were dying, their caregivers, and the community" (p. 333). A study out of Europe by Eva and Morgan in 2018 reported that "Barriers include a limited understanding of the scope of the occupational therapy role; limited resources; and few OTs engaged in service development, leadership and research" (p. 966). Rahman (2000) completed a qualitative study that also found there was a misinterpreted role. His study found that OT was "defined too much by exercises or functional tasks, and not recognizing functional tasks become even more critical to someone who is becoming weaker and weaker and is in the process of dying" (p. 815).

A survey completed by Knecht-Sabres, Weppner, Powers, and Siesel in 2018 was sent out to explore health care professional's knowledge on OT's role in hospice care. Similar to the other literature the results showed that OT's role is misunderstood and underutilized, but health care professionals do believe that occupational therapy is important to the hospice care team (Knecht-Sabres et al., 2018). The themes found from the study regarding utilization of OT services in hospice were "lack of reimbursement, timing of referral, knowledge of the role of OT, refusal of services by family members, and lack of OT presence in this setting" (Knecht-Sabres et al., 2018, p. 380). The conclusion of this study found that most hospice recipients are not receiving OT and that more consistent and on time referrals may help patients attend to meaningful occupation during end of life (Knecht-Sabres et al., 2018). The five studies discussed above show a clear lack of understanding of occupational therapy's role and value by health care professionals and patients in hospice care.

Funding is another major barrier for OT in hospice care. Keesing and Rosenwax (2011) found that funding is a major barrier for integrating OT and hospice care. Rahman (2000) also found cost to be a barrier, as well as contacting occupational therapists to be a burden for the hospice agencies. He stated, "When hospices did not have an occupational therapist on staff, this created a burden because they had to contact an outside agency and pay for it" (p. 815). He also found that although Medicare covers OT in hospice, hospices often did not utilize it in order to save money (Rahman, 2000). Medicare and hospice have a capitation benefit which means the many services offered have to divide up the available money. Services like nursing, social work, occupational therapy, durable medical equipment, and bereavement counselors all come from the same funds. Therefore, when deciding where to make cuts, OT was often eliminated (Rahman, 2000).

Another barrier experienced by OTs who work in hospice care is the limited education received on hospice care during their time spent as OT students. Dawson and Barker (1995) state "64% of hospice occupational therapists surveyed indicated that they had received no preparation in hospice or palliative care during their undergraduate training, suggesting a need for enhanced curriculum to address this area of care" (p. 119).

There was only one article that discusses hospice in education and fieldwork opportunities written by Folts, Tigges, and Weissman in 1986. Although this study is outdated, it is the only article that describes the direct implementation of a program to address hospice care in the occupational therapy curriculum. In this program, researchers created an independent study program that allowed some students to affiliate with local hospice care agencies around the area. The students were directly involved with care of the patients and meeting with the care team. To begin this process, undergraduate occupational therapy students reviewed the related

literature and reported it to the professors (Folts et al., 1986). To continue preparing for the experience with hospice, the students held mock interviews and practiced answering questions like: "Am I really going to die?" "Why has god done this to me?" "Why am I getting so weak? I thought after surgery I would feel better?" (Folts et al., 1986, p. 624). They decided to complete these mock interviews because during hospice care terminally ill patients may be emotional and ask charged questions. The students also attended all team planning meetings to get to know each profession working on the hospice team and created interventions and treatment plans (Folts et al., 1986). This study aimed to help broaden the OT students' knowledge on the hospice model of health care. The conclusion of the study was that the students gained understanding on hospice care and occupational therapy's potential role and that it helped students become "more sensitive and effective occupational therapists regardless of the field of practice they will enter after graduation" (Folts et al., 1986, p. 628). One student in this study helped the patient therapeutically with planning a 'last luncheon' with her friends by assisting with bathing, grooming, and planning for the party (Folts et al., 1986). Although it seemed to be a positive learning experience for OT students, it is unclear if this program continued.

End of Life Calling for Occupational Therapy

There is a large amount of research on end of life in general, completed by other health care professionals who identify the need for services, which could be provided by OTs, although they may not know to call it such. Other OTs have identified this need. For example, Chase (2010) an OT wrote in reaction to an article about palliative care and quality of life in lung cancer patients, that her "initial reaction to the article was surprise, but that response was short lived as I considered the potential meaning behind the results and the connection to the philosophy of our profession" (p. 2). Additionally, many articles use language that has direct

links to OT, focusing on participation and the role of activities in the quality of end of life. For example, a recent qualitative study that interviewed ten cancer patients at the end of life found that their disease affected their ability to participate in occupations (Morgan et al., 2015). The article stated that, "relentless bodily breakdown disrupted peoples' relationship with time, hindering their ability, but not their desire to participate in everyday activities" (p. 185). They may not be referring to OT directly, but participating in everyday activities is at OT's core. In 2008, the National Coping with Cancer project published a study to determine whether end of life discussions are associated with fewer aggressive interventions like, ventilators, chest compressions, and oxygen machines. This study found that, "End of life (EOL) discussions are associated with less aggressive medical care near death and earlier hospice referrals. Aggressive care is associated with worse patient [quality of life] and worse bereavement adjustment" (Wright, Zheng, & Ray, 2008, p. 1665). This study raised a greater issue that needs to be addressed in the health care system. If hospice referrals can begin earlier, then occupational therapists may have more time to complete more thorough treatment addressing ADLs and meaningful occupation. Although rehabilitation is not at the forefront of hospice care and that is what OT's role typically is, hospice "is concerned with maintaining autonomy and independence in patient's lives, despite limitations, and this is in perfect alignment with occupational therapy goals" (Russell & Bahle-Lampe, 2016, p. 3).

Dr. Atul Gawande addressed end of life in his book "Being Mortal." Gawande (2017) suggests that patients who may be terminally ill are not just focused on getting better, but also on decreasing suffering, strengthening relationships with family friends, being mentally aware of what is going on, not being a burden to caregivers and feeling a sense that their life is complete. Russell and Bahle-Lampe (2016) state, "Research has demonstrated that end-of-life occupations

are centered around the maintaining of and engaging in relationships, a sense of purpose through impact on the environment and active engagement in reflection on life" (p. 3), which coincides with what Gawande discusses. Also coinciding with pain management and decreasing suffering techniques, Marcil (2006) states, "activities and occupations can serve as a diversion from pain … When one participates in an activity that brings one pleasure, the body produces endorphins, the body's natural painkillers" (p. 29). Therefore, OTs can focus on what people want to focus on at the end of life and consider their services evidence based.

Gaps in the Current Literature

Although OTs have notable and appreciated roles in hospice care, there is a significant gap in the literature. This consists of the extremely limited research on the day-to-day activities and personal accounts of OTs working in hospice care. In addition, the small amount of literature addressing OT's role is outdated. With the rapid changes in health care delivery, up-to-date information is crucial in defining OT's role in this area of practice.

Chapter 3: Methodology

Design and Procedure

In designing this study, I chose to use qualitative methods because I was interested in accessing the personal accounts of what actual OTs were doing in hospice care. Narrative techniques and interpretive phenomenological analysis were used to collect and analyze data. The study included semi structured interviews used to elicit these experiences with a total of four participants. The interviews were carried out over the phone, each participant had two interviews, 30-45 minutes in length, making a total of eight interviews.

This study focused on the narratives told by the participants. Narrative interview techniques encouraged participants to tell specific stories about the topic of interest. Analysis of which narratives participants choose to share created "a window into how these therapists [were] assigning meaning" (Bambrick, Dennis, and Wilkinson, 2018, p. 4). By listening to these narratives, the researcher was able to form an understanding of the participants' day-to-day experience in hospice care. An interview guide was developed by the researcher in consultation with a faculty expert in narrative interviewing techniques to help guide the interviews. Questions were designed specifically to elicit narratives. The interview guide can be found in Appendix C. Asking therapists to narrate this level of specificity can also provide access to the day-to-day meaning-making decisions that occur in the lived world of daily practice (Mattingly, 1991; Mattingly & Fleming, 1994).

Interpretive phenomenological analysis (IPA) was used to analyze the data. IPA involves exploring what is present in the data and interpreting it through the researcher's own lens. It is best used with data collected through semi-structured interviews (Smith & Osborne, 2007). IPA

can be described as, "understanding people's everyday experience of reality" (Braun & Clark, 2006, p. 84). This is typically done by exploring the participants' experience in depth and is focused on the individual's perception of the experience as seen through the researcher's interpretive lens (Smith & Osborne, 2007). IPA acknowledges that the researcher cannot completely get an insider's perspective, and that the researcher's role "is concerned with trying to understand what it is like, from the point of view of the participants" (Smith & Osborne, 2007, p. 517).

Data Collection and Analysis

Each of the eight interviews were audio recorded and transcribed using the online service Temi (2019). Transcripts were reviewed and corrected by the researcher while listening to the audio. Field notes were written during and after the interview process to note initial observations. An iterative process was used to develop further questions using field notes and first interview transcripts. This process consisted of discussing the transcribed interviews with my faculty supervisor. We then reviewed the literature and data in order to create questions that would deepen the understanding of the participant's experience and support development and confirmation of emerging themes.

There are many ways to analyze qualitative data (Braun, 2006). I chose to use thematic analysis through an interpretive phenomenological and narrative perspective for this study. This method can be defined as, "a method for identifying, analyzing, and reporting patterns (themes) within data" (Braun & Clark, 2006, p. 82). I used a method based on the work of Cheryl Mattingly (1994). This method involves chunking the data into chapters and naming the chapters. These chapter names are then collected as a whole and analyzed to find common themes within and across cases. Themes were defined as, "something important about the data in

relation to the research questions" (Braun & Clark, 2006, p. 87). The themes were ideas that came up multiple times or ideas that stood out in the transcript. Themes were discussed and modified by the researchers frequently. Data analysis was completed by me, a committee member with content expertise, and my faculty advisor. Each read the data independently and developed themes. We then used a process of triangulation to review the themes to ensure I and my committee members reached similar results from the data. The themes were reviewed and connected to the research questions and the literature.

Participants

After receiving IRB approval at Ithaca College (see Appendix D), the recruitment process began using snowball sampling. I began recruiting by reaching out to a recent author on this topic who had published a piece in a professional magazine. This person was able to refer me to additional therapists who were working in the field. I asked those people in turn to refer any other therapists they knew who might be willing to participate. I continued this process until I had found four therapists who were working in the field of hospice who were interested in participating in the study. The interviews began once a signed consent form and non-disclosure agreement was received back from each participant (see Appendices A and B). Each participant received a $40 Amazon gift card for completion of the study to thank them for their time. *Table 1* presents an overview of the participants' characteristics. One limiting factor of this recruitment design was that three of the four therapists worked for the same employer. Since so few therapists are working in hospice care and there was still significant variety of perspectives from these four therapists, after consulting with my faculty advisor I decided that this would still allow me to collect meaningful data. Finding the final therapist who worked in a different

geographical location and employer, helped me to ensure that themes were not unique to the setting that the other three therapists worked in.

Table 1

Participant Characteristics

Participant	Years as an OT	Years worked in hospice
Dave*	24	13
June*	2	2
Elaine*	29	24
Norah *	12	6.5

Pseudonyms used to protect participants' identities.*

Reliability and validity

To ensure reliability and validity of this study each interview was transcribed using an electronic program, each transcription was reviewed and corrected by the primary researcher. My faculty advisor, Dr. Wilkinson, and committee member, Ms. Pasquale, reviewed the data multiple times and discussed analysis and themes with me. Also, throughout the second interviews I used the member checking technique and discussed themes found with the participants to ensure that I had the right idea about their stories and knowledge.

Chapter 4: Results

Seven major themes emerged through the process of data analysis. These were: *The Barriers, The Hospice Mindset, Collaboration, Little Bit of Rehab, Little Things Big Impact, Participation is Pain Management, Role Release and Partnership.* I will expand on each of these themes with sub-themes as necessary, sharing supporting quotes below. In addition, I will discuss how the themes are integrated and relate to the larger issues within the fields of hospice and OT in the discussion section.

The Barriers

The *barriers* participants discussed were similar to the barriers discussed in the literature review. This confirms that these barriers continue to directly limit the number of OTs working in hospice care. I broke these into two sub-themes: the stigma of rehabilitation and funding.

The stigma of rehabilitation. Because OT is part of the rehab family, most people assume that OTs must make people better. In fact, all four OTs I interviewed commented on how limiting this association of therapy with classical ideas about getting better was in including OT in hospice care. Getting better, of course, could not be the primary goal of hospice care. June stated that most of her patients ask to get stronger and for exercises, because that is their pre-conceived notion of OT. She discussed that once you sit down with the family for a conversation, a larger role for the OT can be uncovered, and this is more than just rehab. Elaine highlighted the difference by stating that typical rehab OTs are: "Working towards the goal that we're going to make them better. It's not as if that isn't the goal you have with hospice OT as well, but it is in a much different way." She also acknowledged the fact that although we may not be making individuals functionally better like a rehab OT, this profession can still play an important role. She said, "part of dying is getting better too. We are facing ourselves darkly in a

way that we don't anytime else." By acknowledging that healing can still happen during the dying process, Elaine was linking the rehabilitative role with the care she provides in hospice, but this is not what most people associate with the care an OT can provide.

Norah further explained the stigma of rehabilitation, by saying that at times families and patients quickly pushed her away. She stated, "I have had people that almost have a sense of PTSD when I come in. The family will say, oh no, [therapists] just push them too hard!" Norah explained that this misinterpretation by the patients and families is related to associating therapy with intense rehabilitation and "workouts." Norah mentioned that it took time to explain OT's role in hospice care to clear up the common misconception.

The stigma of rehabilitation is related to the misunderstood role of OT in hospice care that I noted in the literature review. The confusion between what is rehab and what is OT may limit patients and other professionals from asking for OT and accepting it when it is offered as part of end of life care.

Funding. The second sub-theme barrier is the lack of funding for OT services in hospice care. Similarly, to what was reported in the literature, the participants all reported that most hospices do not directly employ therapy services, as Norah stated, "there is no financial incentive." Dave further explained that it is not a reimbursed service and that the hospice home itself has to cover the therapy and equipment costs. Because funding streams are not obvious, OT services at end of life are often very limited.

The Hospice OT mindset

The second theme that emerged from the data describes the differences in mindsets between a hospice OT and an OT in a more traditional rehabilitation setting. Elaine stated, "My role as an OT in hospice isn't all that different than any other OT in any other setting. It's just, I

am infinitely more aware of the fact…[that] they're not going to end up walking away and living for years." This acknowledgement of the reality of death inherent in hospice care-based services makes occupational therapists' role in hospice unique compared to traditional rehabilitation settings. When discussing the difference between the rehab setting and the hospice setting Norah described, "So in the hospice setting we are really just focusing on what they can do with what they have." This contrasts to the more typical rehab setting where the focus would be on building capacity and regaining function as noted in the previous theme. As a hospice OT, Norah does not focus as much on regaining strength because she is aware that there may not be as much strength to return to as there is in rehabilitation. Norah instead described the focus as "quality of life at the end of life and comfort, which is different than a traditional model of OT which is rehab to get function and regain function or independence." Norah compared hospice OT to rehabilitative OT by stating,

> "So in the Rehab Setting, I'm looking at someone who has had an illness or injury and they're below their baseline. We want to get it back to where they work or even potentially even higher so they can be as independent as possible. So using Ther X ©, …[working] with the cognition they have to be safe and independent in their setting, which is like, you know, repetitive training on how to stand up safely or you know, on a very straightforward rehab they have had a hip, a replacement or knee replacement and regaining independence with all their ADL so they can go and be independent. Whereas in the hospice we're not expecting that to happen, you know what I mean?"

Participants also mentioned that patients sometimes do not understand why they will be receiving rehabilitation in hospice care, therefore explaining the hospice OT mindset is important. Norah discussed this during in an interview by stating,

> The family will say, "oh no, they just push them too hard" but that is not the main point of OT and hospice, ... So, it is really explaining the role of hospice OT because I will go see a family and they will be like "No, uh why!" Let me tell you what we do, any kind of equipment you need, or if the patient is not comfortable in their chair, I am not trying to make them workout.

This quote by Norah shows the specific mindset hospice OT has and that other people may not know the difference. She has to explain it to patients and their families so they also can see the value and the difference of OT in a hospice setting. My other participants shared similar thoughts about this shift in the mindset of an OT when working in a hospice-based setting.

Collaboration

The *collaboration* theme emerged with two important sub-themes, goal reconstruction and listening. In order for a successful therapeutic process to happen in the hospice setting, collaboration is key. That means that the therapist must use their clinical reasoning to judge how best to go about this unique therapy. Collaboration is a theme that focuses on the joint effort made by both the therapist and patient in this process of hospice care.

Goal reconstruction. The goal reconstruction sub-theme describes how hospice OTs may need to work with a patient to reconstruct goals in order for them to be more attainable. If a patient has a goal, the OT uses their clinical reasoning to ascertain if and how that goal can be achieved. Sometimes this means slowing down the goal or adapting the goal. Dave explained the first step of this as, "attending, listening and supporting their goals." He also discussed that "there are times that their goal may not be realistic." This is where goal adaption and collaboration come in to play. He addressed that some goals may need to be slowed down because they cannot be achieved right away, by stating, "they are able to do some things and maybe it's going to be a slower process."

These quotes suggest that the jobs of these OTs in hospice care required listening and acknowledging patient goals and allowing them to be completed at an appropriate pace or adapted in a certain way. Dave gave an example about working with a patient whose goal was to sit up again after not being upright for a while. Physiologically, when the body has been prone

for a period of time, it adapts to the position it has been spending time in so sitting up may cause blood pressure to fall or other medical problems to arise. Dave expands on this by saying,

> "Yes, this is your goal, but why don't we have little goals, uh, that will help us determine that. So, in two weeks, can you have the head of the bed elevated to 70 degrees? Right now, you only have 45 degrees so that you can tolerate things." So anyway, so yeah, it was a little bit of that restructuring their goals and making them more capable and go from there.

Goal adaption or reconstruction may also mean adapting the temporal quality of an occupation. For example, the simplicity of cooking a meal may need to be completed with a longer span of time. Elaine shared an example of such restructuring with a patient. That goal was not attainable due to her declined stamina, so Elaine reconstructed the goal so that the patient could teach her family how to make a favorite recipe. She stated, "Even if they could still sit in the kitchen and they can still talk them through it. I mean right there they are handing it back to each other." Dave and Elaine's examples show how goal reconstruction occurred in hospice care, and that it was appropriate to support achievement of a goal for a patient that was dying.

Listening. For goal reconstruction to work, the OT must listen to the patient's wants, needs, and desires. The importance of listening emerged as another sub-theme in collaboration. As Elaine simply put it, "We as therapists listen." Dave also stressed the importance of listening to the patients so the therapist could "meet them where they are at." He stated that "not pushing your own agenda and getting to know what is important to them" is critical for OT in hospice care. Therefore, listening to the patient is a key component in treatment planning in order to create client-centered practice. Part of this listening practice is doing the work to elicit meaningful narratives. June stressed the importance of probing the patient with more questions to reveal what was meaningful to them. She described how listening carefully could be powerful, "reading between the lines you know … you can get a lot of detail just by what they say and

asking questions, exploring with them." Listening to a patient thoughtfully can open the doors of communication and increase the strength of a therapeutic relationship. June also stated, "You really connect with people and really find that out what is important to them because it just makes their entire experience both as a practitioner and on the patient side to just be all the richer." Listening helped the therapist gain access to the patients' needs and wants and helped strengthen the relationship between the therapist and patient. Deep and purposeful listening was clearly identified as something a hospice OT does every day by all four participants in this study.

Little Bit of Rehab

In many of my interviews, participants shared that they completed *a little bit of rehab*, despite the fact that hospice does not typically focus on strengthening or improving long-term skills. Improved endurance and strength may be required or needed to allow the patients to complete their activities throughout their end of life process. This may mean that rehabilitation would be present in hospice in order to continue participation in meaningful occupations for some patients. This idea that rehabilitation may still be present also showed that OTs do not shut down patient goals even though they are near the end of their life, Dave stated "not shutting the door on them is important." Not shutting the door on them could mean that when an OT was conversing and collaborating with a patient on how to achieve a goal, the therapist had a positive mindset and did not reject the patient's wishes to complete a meaningful occupation. This required an open mind by the OT.

One example of many shared by Norah was about a retired doctor who returned home from the hospital to be on hospice care. He had lost endurance during the hospital stay and had a goal of continuing to attend church services. Norah suggested he use his wheelchair, but he was determined to walk into the church.

> "He's like, "I don't want one. I am not going in a wheelchair, I'm going to walk in." Okay. So that turned into a little bit of a stretch. We do sometimes a little bit of rehab to meet a goal, … knowing that they're going to come back down. … So I went weekly and then he had a private caregiver who would do some of the exercises with him and he got fairly stable with a walker. He was okay with a walker. He just didn't want to use the wheelchair. So, then it became the "here comes the Sunday." He felt strong enough. We all felt good about it. His wife felt good and he walked into his church. He met his goal."

Norah stated that she did "a little bit of rehab" to meet a goal speaks to a role that OT can play in hospice, sometimes working on strengthening the patient even though they are in decline. It was with pleasure in her voice that Norah shared that after participating in the exercise program Norah developed, this patient was able to walk into church with his wife. She acknowledged that she knew that this function would be lost again due to the nature of hospice care, but the little bit of rehab allowed for a temporary improvement in his mobility skills that allowed him to participate in an occupation in a way that was meaningful to him. Knowing these patients were near the end did not mean that the OT could not try to help them meet their goals. Sometimes a little bit of rehab was all they needed to participate in their meaningful occupations a few more times. This theme ties in to the next because the therapist has to use their clinical reasoning to know when the little bit of rehab will work or when alternatively, the activity needs to be adapted to match the patient's abilities.

Little Things Big Impact

Little things big impact was a theme that emerged from many stories of small changes that were easy for these OTs to make but that had a big impact on their patients continuing participation in meaningful occupations. A story told by Norah about a woman with cancer who wanted to play the piano highlights this theme. The patient reported she could not sit on the bench and therefore could not play anymore. Norah noted, "when I looked at her, looked at her piano, the piano bench. I got her a wheelchair and then I kind of like a built up the sides for more

lateral support but keeping her arms free." Norah's goal for this patient was to continue this occupation. Using her professional knowledge about wheelchairs and seating support she was able to help her patient meet this goal. She said,

> "[When we] got the wheelchair in there, in front of the piano. It was like the moment of truth and I thought, oh, I hope cognitively she can…, she was pretty with it, but she had been through a lot of treatment and she was sort of, very weakened. She reached forward, opened her music book, and just started playing beautifully. She was so happy."

As you can see here, Norah's ability to make a simple change, made a tremendous difference in participating in this important occupation during this patient's last months. This was one of many stories that the participants told that included a simple change that allowed a meaningful occupation to continue to happen. In many cases, the patients thought these occupations were lost, but with the OTs' knowledge and skills to make a small change, they could continue to participate in a meaningful activity for a longer time.

The little things these OTs did made a massive difference in how the patients completed meaningful occupations, sometimes for the last time. The theme little thing, big impact noted how important it often was for patients of these OTs working in hospice care to complete a meaningful occupation one last time. Elaine stated, "Sometimes I think when they have the richness of that last experience…, they could lay their bones down." She is referring to letting the patient's body and mind rest once they experience a meaningful occupation one last time, to the best of their ability. She gave the example of a man who wanted to hike outside a few more times, but with the decline of his body, it was not an easy task. He wanted to complete this in a way that was meaningful to him and as such he was unwilling to use a walker on these last few hikes. Elaine offered him an alternative that fit better with how he saw himself and how he wanted to experience the occupation, a walking stick, which he loved. Elaine stated, "He was a hiker and climber and you know, you know I gave it back to him for a while." Giving him back

his hobby of being a hiker for a few final times allowed him to have that rich last experience during his time in hospice care and made a big impact on his quality of life in those last few months.

Dave also told many stories of making a big impact by doing something small. In one such story, he highlighted a rich last experience shared by a patient and her daughter. This experience was facilitated by a little adaptation Dave completed as the OT that made a big impact on the patient's ability to participate in a valuable family occupation. Dave explained that the referral he received from the nurse noted that the patient's daughter got symphony tickets for her Mom, but she was too weak to tolerate the show. Dave saw an opportunity for OT to step in and make this last experience happen for the patient and her daughter. The patient required a neck brace due to a weak trunk, but she did not find it fashionable enough for the show, so Dave suggested an airplane pillow with a pretty design for the patient. The story continues, "The daughter was like, 'I am going to buy this right now!' Then I ordered a reclining wheelchair, so she was able to take that to the symphony." The combination of the reclined position and the neck pillow provided enough support to go without the neck brace. This allowed the patient to participate in a way that she was comfortable in the environment, and as such, she was able to stay for the entire show with her daughter. Dave's problem solving allowed for relatively small adaptations but increased this patient's ability to have a last rich experience, a big impact for her and for her daughter.

Participation is Pain Management

The next theme I would like to discuss is *participation is pain management.* As OTs we center our practice around facilitating participation in meaningful activity. Participation has been known to enhance quality of life, but my participants described another role as well. These

hospice OTs saw a decrease in pain when their patients were participating in meaningful activities. Elaine stresses the importance of this theme when she stated, "If [a patient] is lying in bed and all [they] are doing is laying [in] bed and staring at the ceiling, how much pain are [they] in?" This quote emphasizes that not participating in any meaningful occupation may increase the awareness or feeling of pain to some patients. Elaine's reflection on the pain felt when someone is not participating in meaningful occupation can also be backed up by other OT literature. A study aimed to understand how individuals manage pain found that, "uses of activity were often described as one way to separate body awareness and unexpected pain" (Dudgeon, Tyler, Rhodes, & Jensen, 2006, p. 99). June, another participant, brought up another way occupational therapist use their skills as pain management. She stated,

> You can also see therapeutic use of self as a means to pain management or even a distraction strategy because when you're talking with them and they are engaged, you know, they don't often realize that they are sitting up nice and tall without slouching back and you know they haven't really complained of pain in a while.

June sees that social participation can have physical benefits and allows her patients to experience less pain. She goes on to share a specific story of this phenomenon. June was working with a patient whose body had declined and who was often in a great deal of pain. His OT sessions revolved around social engagement and participation in storytelling. When engaged in this June stated, "He sat up nice and tall, probably better than me… not one time did he have to, you know, ask his wife for his nebulizer treatment or did he complain of pain and pain was a big thing for him." This quote speaks to how engaging in the meaningful occupation of story-telling acted as pain management for this patient. The interviews were full of similar stories. The focus that these therapists held on participation in meaningful activities led them to observe decreases in pain for many of their patients.

Role Release

The *role release* theme came from a single participant's exemplary narrative. Elaine's long career as an OT in hospice care and tendency to reflect deeply on her practice added a layer of richness to her narratives. One area in which this was particularly noticeable was in how Elaine discussed the connection between end of life and meaningful occupation. She focused a lot on roles at end of life, saying:

> All roles are lost when you're facing death, at the end of life. You may still have some and those that you have become very, very precious, but it's such a different way. My goal is not to return people to their roles. My goal is to help them to release those roles into deeper appreciation of who they are as a human being. Separate from all that.

Elaine gave an example of a young woman who wanted to use her favorite hobby, writing poetry, as a way to create final gifts for her family. As her OT Elaine facilitated writing haikus for the patient's family members, allowing the patient to go through a process of "letting go of the role on a really sacred level." As Elaine facilitated participation in the act of creating and completing these gifts, the patient was able to let go of her roles as a family member and as a poet. Elaine felt that allowing her patients one rich last experience helped them to release these roles. This idea of helping to facilitate rich last experience of a meaningful occupation emerged in many narratives in the data and is also discussed above in the Little Things Big Impact theme.

Partnership

Partnership is another theme that emerged from the data that can also be linked to an outside source. In Mattingly and Fleming's (1994) extensive work on clinical reasoning, they came across a definition of OT that differentiated OT from other professions.

> When we asked them [occupational therapists] what made occupational therapy different from other health professions (say physical therapy or nursing) they would say two things. One, occupational therapists cared about function. Two, occupational therapists "do with" their clients. Therapists would say, "Nurses do for patients. We help patients do for themselves (p. 178).

Mattingly and Flemming determined OTs distinct value was “doing with” patients. This can be seen in hospice where the therapist is doing dying with the patients they serve. There were many examples of partnership throughout the participant’s responses during the study. One of them being a metaphor from a single person’s narrative. Walking alongside them as they lay things down emerged from a single participant’s narrative, but I found it to be a powerful metaphor for the work all four participants were discussing. Walking alongside them as they lay things down is an example of “doing with” patients. Elaine described her goal to guide patients to a place of understanding at the end of life. She told a story about a man who owned a llama farm and loved to take long walks every day. Every session they took a walk, as the man’s illness progressed, the walks got shorter and shorter. She felt that the shorter walks helped him make peace with his progression towards death. She stated, “I knew that he finally recognized his own death because he was able to face his loss step by step and that I walked alongside him literally in that journey.” He passed away a week after he discontinued his walks in OT. Elaine explained her metaphor by saying,

> So in a way that sort of explains how I, how I do hospice. That's kind of like a concrete example. It's walking alongside of people as they lay things down. It's not about me helping them to do it. It's me being willing to walk alongside them as they understand what's happening.

This metaphor captures the partnership that patient and therapist build in day-to-day practice. As I mentioned in collaboration about the importance of listening, it appeared that listening can have another meaning in this setting. Elaine stated, “they invited me into silence more than they did invite me to talk.” This quote provided an example of the unique way OTs “do with” their patients. Whether it is literally walking next to them, sitting next to them, or being silent with them, these OTs were always “doing with” their dying patients.

Although they may not have labeled it with this metaphor, other OTs also referred to this. It seemed as if they all were right beside patients, step-by-step towards the end of the journey. Dave told a story about a woman on hospice who wished to see her garden one more time.

> Monday morning, I get the referral and I am able to go out the next day because she is not doing well. Through our DME company I ordered a reclining wheelchair and a Hoyer lift and I go out there to her house and we are able to get the patient out of bed… so we wheeled her out to her huge bay view windows where she was able to see her garden and she was crying, her husband was crying, and then her mom because the patient was 55, her mom was there too. She was crying. We were all crying. And she passed away the next day.

This story was similar to the walking alongside them story about Elaine and her patient from earlier in this paper. By getting to know the patient's desires and needs at the end of life Elaine and Dave were able to help them get there. In this case, it was getting the appropriate equipment needed for her to participate in this meaningful activity. Dave shared that he cried with this family, showing how he "does dying" with the patients and families that he serves.

Another antidote told by Elaine emphasized "doing with" a patient, even when the family was not emotionally able too. Elaine stated,

> I remember once I went to see this woman that I've never seen before and [the family] couldn't get her to the hospital bed and partly it was, I don't think [the family] wanted too. So, I got her into the hospital bed, and I got her situated and I sat in a chair next to her bed. They were so scared of death. They were all sitting in the other room, I was sitting in the chair. I finally sat down long enough for them to come and sit in the chair, then I could leave.

This reflection by Elaine on a time that she sat with the patient until the family came and joined, showed another way the OT could "do with" a patient or their family. This example highlighted that the OT can also "do with" the family. Elaine stated one of her interventions is, "to help the family to be present with the patient in their dying process." Involving the family was another way that this OT has found to be helpful during the hospice care process.

Whether it was literally walking with them, involving family, or doing behind the scenes work to get adaptive equipment, the therapist was physically or literally walking alongside the patient as they went through the end of life process. These OTs working in hospice care were able to "do with" the dying and as such integrated occupational therapy and hospice care.

Chapter 5: Discussion

Clinical Implication & Future needs

The findings of this study describe the role of four OTs in hospice care, the barriers they experienced in providing OT in hospice care, and the specific mindsets of these OTs in hospice care. These narratives provide a clear example of how meaningful OT can be in the hospice care setting.

The distinct value of OT is the unique characteristics we bring to the table that other professions may not. Amy Lamb (2016), past president of AOTA, described this distinct value of OT is "to improve health and quality of life through facilitating participation and engagement in occupation, the meaningful, necessary, and familiar activities of everyday life" (p. 4). She went on to note that "occupational therapy is client-centered, achieves positive outcomes, and is cost-effective" (p. 4). Trump et al. (2005) also states that an OT's "personal awareness and deep understanding of the meaning of occupation makes a powerful contribution to the process of caring for the dying person" (p. 674). Therefore, OTs focus on participation and meaningful activity is one of the profession's valuable characteristics. One of the participants, June recognized that OTs bring "a different vibe" in hospice care. She stated, "with occupational therapists, … , in a way we are kind of seen as, not the fun ones, but the ones that people look forward to because it enables them to do something." This quote speaks to the focus on independence these occupational therapists bring, the distinct value of OT in this hospice care setting.

The power of autonomy is an idea that highlights OTs' value of independence and how they can still bring that to hospice care. OT has a unique value that focuses on independence and participation in meaningful occupations for the patients they serve (Lamb, 2016). This can be

linked back to how occupational therapists practice in hospice care. For example, the seemingly little things that these OTs did had a big impact on their patients' abilities to complete meaningful occupations right up until the end of life. Elaine's story about the hiker is a great example. Using her clinical reasoning skills, she was able to make this happen by providing him with a walking stick. Elaine's work with this patient provided him with the autonomy and independence to go outside and hike a few last times. This story highlights the distinct value and focus occupational therapists have on promoting engagement in meaningful occupation.

Although the patient is dying, independence is still valued by these OTs. Perhaps, it is that they did not focus on the death. June stated, "I think we (OT) were a breath of fresh air for them… you know, we don't treat them like they are dying." By enabling patients to perform activities, the OT may provide a sense of normalcy to the patient's life that gives them a sense of autonomy.

As the autonomy is important for the patient, the caregiver, and family may also find appreciation. One participant discussed that some families are surprised at what the patient can still achieve independently. They stated, "They're amazed at what they would do, or what the patient is able to do that they didn't think that they could do…I think there's a focus on independence in a way." This quote speaks to the idea that patients can still maintain autonomy in some ways towards the end of life, although this may surprise their family. Dave stressed the importance of autonomy by stating, "People get to do something that they were not able to do and that has deeply brought joy to them, not just them, but to the family as well." This quote also embodies the importance of autonomy to the family and caregivers, seeing a loved one do something independently one last time can create a special memory.

June offered another look at autonomy by discussing that OT gives people an option to complete a meaningful activity with facilitation. She discussed that giving her patients the option to go outside was offering more autonomy. These OTs built a client-centered relationship with their patients that often created a unique bond between patient and therapist allowing the individual to share what was meaningful for them. The therapist could then use their unique OT lens and clinical reasoning to make patients' goals achievable. Although creating partnerships and collaborating to make goals reachable is not listed as a distinct value in the literature, I believe that it is an important value of OT practice. Building this relationship creates a platform for success throughout the therapy sessions. Tickel Degnen (2002) stated that, "that respect and collaboration elements of the therapeutic relationship were important predictors of rehabilitation outcome" (p. 470). I would argue that the therapeutic relationship cannot only just affect rehabilitation but can improve participation in meaningful activity in end of life care.

This also shows up in how OTs approach pain management. The idea that participation can affect pain management is an idea that goes back to one of the founders of OT, Adolf Meyer. Meyer emphasized a connection between mind and body and the importance of completing occupations meaningful to the client (Kielhofner, 2009). In as early as 1892, Meyer identified that "the proper use of time in some helpful or gratifying activity" could affect the treatment of patients (Bryant, Fieldhouse, Creek & Lougher, 2014, p. 8). Early OT' theories support the idea that participating in meaningful activity can act as pain management, whether it be mentally or physically. This focus on participation brings a unique form of pain management to the table.

Most OTs have been trained to focus on not only the patient, but also the family. An OT who practices family-centered care will have interventions that are "rather directed at the heart of how the family meaningfully participates in their day" (DeGrace, 2003, p. 349). For example, in

the *Partnership* theme, Elaine is thoughtful in how she waits with the patient until a family member has joined. This example shows that it is important for family-centered care to be a focus for OTs that work in hospice care.

Another strength of OTs in hospice care pointed out in many stories told by participants during this study, was the ability to complete task analysis or activity analysis. Creighton's (1992) foundational work defines the process of this analysis as,

> first places the activity within a cultural and environmental context. Then both its generic properties (e.g., steps, tools used, cost, safety considerations) and its characteristics related to a specific frame of reference are described. The activity is discussed as it is normally performed and as modified for remedial or compensatory applications with patients (p. 47).

Being able to breakdown an activity and modify or adapt the activity is a key aspect of OT's skillset. One example of many of activity analysis can be seen in the theme *Little Things Big Impact*. Norah refers to a story about a woman who wants to play the piano again. In order for that to happen, Norah had to complete a thoughtful break down of the activity to come up with ways to modify and adapt the seating for the patient. If not for the OT, Norah, and her ability to look at an activity and break it down, this may have not been an attainable goal for the patient. OTs ability to have clinical reasoning with a focus on problem solving and activity analysis allow them to have a different and in-depth view of the activities of everyday life. Although the participants did not directly mention activity analysis, it is clear it was used in their everyday practice. This may be because it has become tacit knowledge that they complete this, because activity analysis is embedded heavily in OT curriculum. Tacit knowledge can be defined as, "the kind of knowledge that is difficult to transfer to another person by means of writing it down or verbalizing it." Mattingly (1991) stated,

> It is argued that clinical reasoning involves more than the ability to offer explicit reasons that justify clinical decisions because it is also based on tacit understanding and habitual knowledge gained through experience (p.1).

To conclude, one participant highlights the distinct appreciation for OT in hospice care,

> I would think if you have any experience in hospice and if you've experienced OT and hospice, that would be, you would never turn away having a hospice OT because OT is so much looking at the whole picture, not just the patient but their family. And the complete goal is at the comfort, safety and quality of life, at the end of life.

This quote highlights the unique aspects OTs bring to hospice care and how valuable that could be. OT has the skillset to address not the only the patient and their quality of life, but the family and caregivers as well.

OT Theory and Hospice

Although theory was not explicitly brought up during most of the interviews, many of the participants' decisions were clearly influenced by theoretical constructs. In listening to their stories about their clinical decision-making process, I could make clear links to established theoretical work in the OT literature. For example, part of our concentration on autonomy and independence comes from the theory background OTs all receive as part of their professional education. Throughout the findings of this study there are many clear examples of how these OT theories can be easily applied in this setting. The Person, Environment, Occupation, and Performance Model (PEOP), first proposed by Law, Cooper, Strong, Stewart, Rigby, & Letts (1996) can explain much of the theory being used by the participants in making these clinical decisions. The main assumption in this model is that "occupational performance is influenced by the relationship between the person and environment" (Cole & Tufano, 2008, p. 127). Therefore, this theory guides the OT to make adjustments to the environment and person to enhance performance in the person's desired occupations. As referenced in Norah's story about the woman playing the piano, a little change in the environment allowed her to participate in a

meaningful occupation. This was one example of many in which the participants used the principles of PEOP to guide their practice even though they were not explicitly describing it as such. June did directly, state that her most frequently used theory was PEOP. She explained that because most of her visits take place in the person's home environment attending to basic needs, she identified that her role involved adjusting the environment in order to facilitate success with basic needs like toileting. PEOP allowed her to think about all of the important components of making a specific activity work in a specific context for a specific person with all of the complexities inherent in each of those categories.

The Model of Human Occupation, or MOHO, is another theory that is commonly used to guide OT practice and was apparent in the descriptions of working with hospice care patients that these participants provided. Keilhofner (2007) defined MOHO as a theory that seeks to explain how occupation is motivated, patterned, and performed. It is a client-centered theory that allows each individual's characteristic to guide therapy (Costa & Othero, 2012). Catastrophic change is a concept of MOHO that Kielhofner (2007) defines "as a stage of change that occurs in a person's life when internal and external circumstances dramatically alter their occupational situation, requiring a fundamental reorganization" (p. 19). Catastrophic change in this sense would be the terminal illness diagnosis and affects many of the core concepts of MOHO, which are volition, habituation, values, performance, and roles. One example of many from this data is Norah's story about the patient whose habit of going to church was disrupted by his illness. His performance, roles, and values were all affected by this catastrophic change to his bodily system. Again, while the OTs interviewed for this study did not explicitly define their practice as being guided by MOHO, their tacit knowledge about these fundamental values within

the OT profession helped to guide their creation of client-centered therapy sessions in hospice care. Further exploration of this theory and hospice care is recommended.

Although these important theories clearly support the practice of OT in hospice care, in practice, OTs are rarely present in this unique setting. The rich descriptions from these four OTs with experience in the field clearly articulate the roles OT can take in working with people who are dying. As such, it is clear that OT is under represented in hospice care.

Implications for Occupational Therapy

Making suggestions and advocating for the OT professions place in hospice care is important to focus on. My suggestions start with academia. Because, there are limited academic and fieldwork opportunities in hospice care (Folts et al., 1986, Dawson & Barker, 1995). Much of what students learn in OT school is applicable to hospice care, yet there is no ACOTE standard that relates to hospice care in the current Accreditation Council for Occupational Therapy Education (ACOTE) standards. These standards provide the guidelines for what OT education curriculums have to include. Because hospice care is not included in the ACOTE standards, academic institutions are less likely to spend time on this topic throughout the OT education. This is a barrier for increasing the presence of OT in hospice care. The educational standards review committee update these standards regularly. The update process includes requesting input from members of the profession in development of new standards. Without an ACOTE standard regarding hospice care, OT programs are less likely to include the topic in their curriculum. One way to advocate for hospice care is to be apart of the AOTA review of standards process.

As seen in the literature (Pitzin, 2009, Rahman, 2000, Keesing and Rosenwax, 2011, Eva and Morgan, 2018, etc.), OT's role in hospice is misunderstood or misinterpreted by other health professions in hospice care and by patients and families. Therefore, it is crucial that OT increase awareness of our role in hospice care. Increasing awareness of our role will also help increase our presence; this can be done by presenting at national conferences about this topic and continuing to encourage research on this topic. We also need to increase advocacy for more funding in this area, the more money allocated to this important time in life, the more access we will have to this population that is in need of OT services.

Limitations

One limitation of this study is I am a novice researcher and despite my extensive preparation and training with my faculty advisor, this is my first independent research study. As a novice researcher I may have missed opportunities to pursue narratives during interviews and to develop follow-up questions that would expand the analysis. Secondly, based on the similar geographical location and three subjects working for the same employer, it is likely I found less variety in the results than would otherwise be expected. Though I was not attempting to gather a representative sample in order to make broader generalizations, it may have been beneficial to have a wider range of experiences in order to develop the richest possible themes to describe the work and perspectives of these particular therapists. Lastly, for the sake of convenience, the interviews were completed over the phone, which meant there was no visual observation of the participant and they were unable to see me as well. Though I do not feel that this was a major limitation, there could have been subtleties of tone that may have been picked up with the visual

cues of body language and participants may have been more comfortable if we'd been able to meet in person.

Conclusion

The rich stories told by the four participants in this study provide examples of how OT can have a meaningful and productive role in the hospice care setting. The requirements and skills needed to be a hospice OT are embedded in OT education and are backed up by prominent theories within the discipline. Therefore, it is important that the role of OT in hospice care continues to be defined and OTs presence in end of life care can continue to be established.

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Appendices

Appendix A. Informed Consent Form

INFORMED CONSENT FORM

Occupational Therapy and End of Life Care: Thoughts from Occupational Therapists in the Field

1. Purpose of the Study

The purpose of this study is to explore the thoughts and ideas of occupational therapists regarding what they can provide in hospice. The questions will search for answers on whether we should or should not work in hospice, what does OT look like in hospice care, whether or not dying is considered an occupation and how we can advocate for our services on a palliative care team.

2. Benefits of the Study

This study will benefit me as a student because it will allow me to complete the requirements for my master's thesis in the occupational therapy program. There is also a potential for scholarly publication. **Possible benefits to the participants include receiving a gift card for $40 for completing the study and self-reflection by talking about their career as an OT who works in hospice care. Each participant will receive the same amount of money on the gift card.** Possible benefits to the profession include increasing others awareness on how OT can benefit a palliative care team.

3. What You Will Be Asked to Do

This study will be qualitative and information will be collected through semi-structured interviews with three occupational therapists working in the field of palliative care. Each therapist will be interviewed two or three times. The first and second interviews will last 30-45 minutes. The third interview will be only 20-30 minutes if needed to answer follow up questions. Therefore the maximum amount of time required by the participants is 120 minutes and the minimum amount of time being 80 minutes. The interview style will be narrative and conversational style guided by the interview guide (see appendix)

4. Risks

This study has few ethical issues and risks of participation. There is a risk that a participant could take time out of their workday to complete the study leading to difficulties during their workday. This can be avoided by completing the study during their free time. Scheduling will be done at times that the participant states are good times for them to talk for 30-45 minutes. **There is no risk to the person's job if they report something negative because of the pseudonyms used in the report. I will ask the participants to use pseudonyms for their patient's names to keep anonymity.** There is a minimal risk a participant will have an emotional response to the questions related to hospice care, but because this is a professional who works in the field and manages their emotions every day it is very unlikely that this would occur. If a participant does have an emotional reaction during the interview, I will offer to stop the interview to allow them time to compose themselves if they wish. **The participant is allowed to withdrawal at any time. If a participant does decide to withdrawal, the audio files will be immediately deleted.** If a participant becomes upset by a question I will notify my faculty advisor who will follow up with an email to check in with the participant and offer resources if necessary.

5. Compensation for Injury

Not needed.

6. If You Would Like More Information about the Study

If you have any questions throughout the study feel free to contact myself (Hannah Schaefer) by email at: hschaefer@ithaca.edu or by phone (585) 410-1615.

7. Withdraw from the Study

The subjects are free to withdraw at any time without penalty, and to omit answers on questionnaires that they feel uncomfortable answering. **If the participant withdrawals, their previous responses will be deleted immediately.**

8. How the Data will be Maintained in Confidence

The interviews will be recorded using a digital voice recorder and saved on a computer that is password protected. Only myself, my advisor, and committee member will have access to the password. Transcripts will be created from the audio data using pseudonyms. Hard copies of consent forms, the pseudonym list, and transcripts will be kept in Dr. Wilkinson's office for a minimum of 3 years. **Dr. Wilkinson's office can be found at 953 Danby Road, 204 Smiddy Hall, Ithaca, NY 14850.** Audio files will be destroyed after transcripts are complete.

I have read the above and I understand its contents. I agree to participate in the study. I acknowledge that I am 18 years of age or older.

_____

Print or Type Name

_____ _____

Signature Date

I give my permission to be audiotaped (videotaped).

_____ _____

Signature Date

Appendix B. Client Non-Disclosure Agreement

CLIENT NON-DISCLOSURE AGREEMENT

This CLIENT NON-DISCLOSURE AGREEMENT, effective as of the date last set forth below (this "Agreement"), between the undersigned actual or potential client ("Client") and **Rev.com, Inc./Temi** ("Rev.com") is made to confirm the understanding and agreement of the parties hereto with respect to certain proprietary information being provided to Rev.com for the purpose of performing translation, transcription and other document related services (the "Rev.com Services"). In consideration for the mutual agreements contained herein and the other provisions of this Agreement, the parties hereto agree as follows:

1. Scope of Confidential Information

1.1. "Confidential Information" means, subject to the exceptions set forth in Section 1.2 hereof, any documents, video files or other related media or text supplied by Client to Rev.com for the purpose of performing the Rev.com Services.

1.2. Confidential Information does not include information that: (i) was available to Rev.com prior to disclosure of such information by Client and free of any confidentiality obligation in favor of Client known to Rev.com at the time of disclosure; (ii) is made available to Rev.com from a third party not known by Rev.com at the time of such availability to be subject to a confidentiality obligation in favor of Client; (iii) is made available to third parties by Client without restriction on the disclosure of such information; (iv) is or becomes available to the public other than as a result of disclosure by Rev.com prohibited by this Agreement; or (v) is developed independently by Rev.com or Rev.com's directors, officers, members, partners, employees, consultants, contractors, agents, representatives or affiliated entities (collectively, "Associated Persons").

2. Use and Disclosure of Confidential Information

2.1. Rev.com will keep secret and will not disclose to anyone any of the Confidential Information, other than furnishing the Confidential Information to Associated Persons; provided that such Associated Persons are bound by agreements respecting confidential information. Rev.com will not use any of the Confidential Information for any purpose other than performing the Rev.com Services on Client's behalf. Rev.com will use reasonable care and adequate measures to protect the security of the Confidential Information and to attempt to prevent any Confidential Information from being disclosed or otherwise made available to unauthorized persons or used in violation of the foregoing.

2.2. Notwithstanding anything to the contrary herein, Rev.com is free to make, and this Agreement does not restrict, disclosure of any Confidential Information in a judicial, legislative or administrative investigation or proceeding or to a government or other regulatory agency; provided that, if permitted by law, Rev.com provides to Client prior notice of the intended disclosure and permits Client to intervene therein to protect its interests in the Confidential Information, and cooperate and assist Client in seeking to obtain such protection.

3. Certain Rights and Limitations

3.1. All Confidential Information will remain the property of Client.

3.2. This Agreement imposes no obligations on either party to purchase, sell, license, transfer or otherwise transact in any products, services or technology.

4. Termination

4.1. Upon Client's written request, Rev.com agrees to use good faith efforts to return promptly to Client any Confidential Information that is in writing and in the possession of Rev.com and to certify the return or destruction of all Confidential Information; provided that Rev.com may retain a summary description of Confidential Information for archival purposes.

4.2. The rights and obligations of the parties hereto contained in Sections 2 (Use and Disclosure of Confidential Information) (subject to Section 2.1), 3 (Certain Rights and Limitations), 4 (Termination), and 5 (Miscellaneous) will survive the return of any tangible embodiments of Confidential Information and any termination of this Agreement.

5. Miscellaneous

5.1. Client and Rev.com are independent contractors and will so represent themselves in all regards. Nothing in this Agreement will be construed to make either party the agent or legal representative of the other or to make the parties partners or joint venturers, and neither party may bind the other in any way. This Agreement will be governed by and construed in accordance with the laws of the State of California governing such agreements, without regard to conflicts-of-law principles. The sole and exclusive jurisdiction and venue for any litigation arising out of this Agreement shall be an appropriate federal or state court located in the State of California, and the parties agree not to raise, and waive, any objections or defenses based upon venue or forum non

Appendix C: List of Interview Questions

1. How did you get involved with OT and hospice?
2. Can you describe a session from start finish you did this week?
3. Can you tell me about the top 5 interventions you complete?
4. Can you give me an example of a time you used meaningful occupation during treatment?
5. Can you tell me about a time when meaningful occupation helped a client come to terms with the end of life?
6. Do you find that your treatment helps take pressure of caregivers of the patient?
7. Why do you think there is not more OTs working in the hospice setting?
8. Does the OT curriculum affect why more OTs do not work in hospice?

Appendix D: Human Subjects Review Board Approval Letter

December 4, 2018

Hannah Schaefer, Graduate Student
Department of Occupational Therapy
School of Health Science and Human Performance

Re: IRB 0918-03b - Occupational Therapy and End of Life Care: Thoughts from Occupational Therapists in the Field

The Institutional Review Board for Human Subjects Research (IRB) authorizes your request for revisions to the above-named proposal. This approval is issued under the Ithaca College's OHRP Federal-wide Assurance #00004870 and will remain in effect for a period of one year from the date of authorization. Approval is contingent on also adding the following sentence to the proposal:

"Confidentiality of patient names used in interviews will be changed when reported."

Please add the IRB approval number (IRB **0918-03b**) to ALL recruitment and consent materials.

After you have finished the project (when data collection is complete and there is no further risk to human subjects), please complete the *Notice-of-Completion Form* found on the Sponsored Research website. Please note that review/approval of future proposals is contingent upon submission of this form.

Should you wish to continue the approved project beyond the expiration date you may request an extension by sending an email to irb@ithaca.edu before September 27, 2019. The project can be extended up to three years. *If the project expires, you must complete a new application for expedited review.*

Please note that if there are any adverse events resulting from this research, they must be reported to the IRB at irb@ithaca.edu.

Sincerely,

Warren J. Calderone

Warren Calderone
Director of Corporate, Foundation Relations, and Sponsored Research
Institutional Review Board for Human Subjects Research